

Article

Improving healthcare for people with learning disabilities, autism or both: A co-produced research project.

Doherty, Alison Jayne

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What helps and holds back healthcare

Little research on how to improve clinical care from the perspectives of people with learning disabilities or autism has been carried out. A project led by **Alison Doherty** and self-advocacy group **Pathways Associates** sought to address this

Numerous studies have shown that people with learning disabilities and/or autism have higher rates of long-term health conditions and die earlier than other people in the general population (Emerson and Hatton, 2013).

Despite this, it has been shown their access to health services is poor and their health needs are often unmet.

In addition, little research on this from the perspectives of people with learning disabilities or autism has been carried out. To address this, a co-produced research project to look at facilitators and barriers to better healthcare was undertaken in the northwest of England.

People with learning disabilities were involved in the co-production of research design, questionnaires and easy-read research findings.

Findings

Hospitals

Participants found hospitals overwhelming and impersonal, and they caused anxiety in several people.

"Sometimes you have to make sure the room is a bit quiet, so you are not getting a bit anxious."

Participants said they had been anxious about finding their way around hospitals, which could be an "absolute nightmare".

Families indicated that they often needed to visit several hospitals to see different healthcare teams and this was not helpful.

Improving healthcare for people with learning disabilities, autism or both: a co-produced research project.

Aims: To identify the barriers and facilitators that people with learning disabilities and/or autism experience in accessing and using healthcare for their general health.

Methods: Group discussions involving 23 people with learning disabilities and/or autism, supported by their carers, were held in January 2019

Read the report: Copies of an easy-read summary of findings are available on request from Alison Doherty at adoherty7@uclan.ac.uk

"All the different hospitals. Each time, there's different people. That impacts. So, for my daughter, my wife and myself are supporting her. She would really struggle and her health would be impeded."

Time

Another barrier was waiting times.

"You can't get an appointment. Then you have to wait about two weeks."

How much time patients could spend with clinical staff was also raised. Some felt they spent more time with their GP than hospital staff; others felt they did not get enough time with either.

Communication

It was sometimes difficult to describe symptoms and people needed more time to process information, particularly if they had other disabilities such as sensory and physical impairments.

People were positive about staff who knew them well, which helped put them at ease.

"He also knows how to treat you if you are uncomfortable with certain things."

Some staff – clinical and non-clinical – did not understand needs and some people had been treated poorly as a result.

"The way they said it. In a nasty way. 'You have to come in at 8 in the morning to make an appointment.'"

Doctors would often talk to a carer or support worker rather than the patient, and this was more likely to occur in hospitals. A good doctor was one who "will look at you and talk to you, not talk to the support worker, because you need to know what's going on".

The lack of up-to-date information in easy-read formats was a particular concern.

"If our son or daughter did not have us as parents going through all this material, they wouldn't be attending anything. Because they wouldn't know."

Not everyone had heard of or had health action plans, health passports or health checks. Participants spoke of the need for consistency in how these were accessed through their GPs.

Fear

Fear was a common barrier and this included fears of needles, health checks, cancer screening and hospitals in general.

People were also embarrassed to talk about their symptoms to staff.



Hospitals caused anxiety as people found them overwhelming and impersonal



on board: the research team identified many reasons why using health services could be difficult, which included staff attitudes and awareness

"It's embarrassing talking about it ... talking about bowels and stuff."

consultation rooms provided by some pharmacists were viewed positively.

"My chemist has got a private room where you can go in and talk to the person."

Technology

Automated phone systems can be a barrier to making appointments, particularly when a caller has to choose between multiple options. Touch-screen technology caused confusion. There was resistance to and mistrust of automated and online services.

"Not everyone has access to computers."

"No – we don't trust anything."

Face-to-face interactions and "personal contact" were preferred, although some valued online healthcare tools and apps.

Support

Support is an important facilitator for those lacking a support network and living alone may not act on health concerns, as a carer suggested.

People who are in supported living ... sometimes don't receive appropriate health care because staff don't support them to attend those appointments."

People with learning disabilities and/or autism often rely on others to support them to attend appointments, so some action should be made for a lack of finance.

Participants identified the need for facilitators to work with people with learning disabilities and/or autism.

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Key points

- Hospitals can be overwhelming and impersonal, and can make people with learning disabilities and/or autism anxious
- Issues related to time, lack of understanding and awareness, communication and technology act as barriers to healthcare
- When staff take time to get to know people, their experience is better
- A healthcare co-ordinator role is needed to improve access to services
- People with learning disabilities and/or autism should co-design improvements to healthcare services

"It comes back to that healthcare co-ordinator. Somebody who will act as your support. And maybe unofficially your advocate almost."

Some people had not considered using pharmacists for help and support.

Training

People with learning disabilities and/or autism need to know how to check for cancer symptoms and how to use medical equipment so could benefit from training.

It was thought both clinical and non-clinical staff needed training. It is critical that any course is provided jointly with people with learning disabilities and/or autism.

Funding could be a barrier.

"We asked our local health nurse and she said: 'Bad luck, guys. There is no money in the budget to train you up to train us up.'"

Additional needs

The participants also spoke of barriers to accessing healthcare that were related to

conditions, such as a lack of home visits for people with agoraphobia.

In addition, some said dental forms needed reviewing as they had been charged wrongly for dental services.

Conclusion

There are several barriers and facilitators to improving healthcare experiences for people with learning disabilities and/or autism.

These often relate to how staff relate to and treat these patients. Raising staff awareness and improving their understanding of patients' needs, for example by providing them with information in easy-read formats or allowing more time in consultations, would greatly improve the experience.

Pathways Associates:
<http://pathwaysassociates.co.uk>

References

Emerson E, Hatton C (2013) *Health Inequalities and People with Intellectual Disabilities*. Cambridge: Cambridge University Press

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Alison Doherty is research associate – evidence synthesis at the University of Central Lancashire